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BILL ANALYSIS

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House Bill 4167 (Substitute H-3 as passed by the House)

Sponsor: Representative Jason Morgan

House Committee: Health Policy

Senate Committee: Health Policy

Date Completed: 10-10-23

CONTENT

The bill would amend Chapter 5 (Prevention and Control of Diseases and Disabilities) of the Public Health Code to create the Rare Disease Advisory Council within the Department of Health and Human Services (DHHS), and to prescribe its membership and duties.

The bill would take effect 90 days after its enactment.

Council

Specifically, the bill would create the Rare Disease Advisory Council within the DHHS for the purpose of advising the Department and other State agencies on research, diagnosis, and treatment efforts related to rare diseases in the State. "Rare disease" would mean a disease that affects fewer than 200,000 individuals in the United States.

Membership

Under the bill, the Council would consist of the Director of the DHHS or the Director's designee and all of the following members appointed by the Director:

- One physician licensed under Part 170 (Medicine) or 175 (Osteopathic Medicine and Surgery) of the Code who had experience treating patients with rare diseases.
- One registered professional nurse licensed under Part 172 (Nursing) of the Code who had expertise in providing care to patients with rare diseases.
- An epidemiologist who practiced in Michigan who had expertise in the incidence, prevalence, and control of rare diseases.
- One individual who represented a hospital located in Michigan; this individual could not be from the same institution as the individual who would engage in rare disease research.
- One individual representing a health insurer.
- One individual representing a health maintenance organization.
- One individual representing the biopharmaceutical industry in Michigan.
- One individual who engages in rare disease research.
- Two parents or guardians of children with a rare disease; each parent or guardian would have to represent a different family.
- Three individuals with a rare disease; each individual would have to have a different rare disease.
- Two individuals representing rare disease patient organizations that operated in Michigan; each individual would have to represent a different organization.
- A medical ethicist who practiced in Michigan.
- A representative from the national pharmaceutical industry or a pharmaceutical company working in the area of rare diseases.
- A genetic counselor licensed under Part 170 who was familiar with rare diseases.

The Director could appoint additional members to the Council that the Director considered necessary or appropriate.

The members first appointed to the Council would have to be appointed within 90 days after the bill's effective date. Council members would serve for four-year terms or until a successor was appointed, whichever was later. A vacancy on the Council would have to be filled in the same manner as the original appointment. An individual appointed to fill a vacancy created other than by expiration of a term would have to be appointed for the unexpired term of the member whom the individual was succeeding in the same manner as the original appointment. The Director could remove a Council member for incompetence, dereliction of duty, malfeasance, misfeasance, or nonfeasance in office, or any other good cause.

A member of the Council would not be entitled to compensation, but must be reimbursed for the member's necessary travel expenses for attendance in accordance with Section 1216 of the Public Health Code (the section concerning travel or other expenses of a public employee).

At any time, the Council could make recommendations to the Director on the appointment of additional members to the Council that the Council considered necessary to carry out its duties.

Meetings

The bill would require the Director to call the first meeting of the Council. At that meeting, the Council would have to elect from among its members a chairperson and could elect other officers as it considered necessary or appropriate. The Council would have to meet at least quarterly, or more frequently at the call of the chairperson or at the request of four or more members.

A majority of the Council members would constitute a quorum for the transaction of business, and a majority of the members present and serving would be required for official action of the Council. The Council would be subject to the Open Meetings Act and the Freedom of Information Act.

Duties & Responsibilities

The bill would require the Council to do all of the following:

- Research and identify priorities relating to the cost-effectiveness of and access to treatments and services provided to individuals with rare diseases in Michigan, and develop policy recommendations aimed at preventing discrimination against individuals with rare diseases with respect to the cost-effectiveness of and access to treatments and services and other related issues.
- Identify best practices for rare diseases from other states and at the national level that could improve the education, care, and treatment of, and services and supports provided to, adults and minors with rare diseases in Michigan.
- Coordinate with other rare disease advisory bodies, community-based organizations, and other public and private organizations in performing its duties to ensure greater cooperation between Michigan, other states, and the Federal government regarding the research, diagnosis, and treatment of rare diseases, by disseminating the Council's research, findings, and recommendations when appropriate.
- Serve as an advisory body on rare diseases to the Legislature, the Governor, the DHHS, and other State agencies.
- Research and make recommendations to the Legislature and the DHHS on the most appropriate method to collect data on rare diseases.

- Provide information or advice on rare diseases to the DHHS or Governor, as the Director or Governor considered necessary or appropriate.
- By December 21, 2023, assist the DHHS in developing a publicly accessible webpage on the Department's website on rare disease resources; the webpage would have to include a list of rare diseases that predominately affect geographically disadvantaged communities and content on rare diseases, including links to websites on rare diseases and resources on rare diseases that the Council and the DHHS consider useful to individuals with rare diseases and the general public, and the Council would have to annually review and recommend changes to the webpage to the DHHS.
- Investigate rare diseases from the list described above and make recommendations to the Legislature on the rare disease.
- Beginning December 21, 2023, and by December 21 of every other year beginning after the first report was submitted to the Legislature, submit a written report to the Legislature on the Council's activities, findings, and recommendations.

The Council also could do one or more of the following:

- Hold public hearings and make inquiries and receive comments from the general public to assist the Council in developing recommendations.
- Consult with experts on rare diseases to assist the Council in developing recommendations, including experts from the private sector, organized labor groups, government agencies, and institutions of higher education.
- Subject to appropriation, apply for and accept grants and gifts from government, nonprofit, and private sources.

The DHHS would have to provide clerical and administrative assistance to the Council in applying for grants, as the Director considered necessary or appropriate.

Any findings and recommendations made by the Council would have to be based on medical or scientific evidence.

Proposed MCL 333.5135 & 333.5135a

Legislative Analyst: Alex Krabill

PREVIOUS LEGISLATION

(This section does not provide a comprehensive account of previous legislative efforts on this subject matter.)

The bill is a reintroduction of House Bill 4654 from the 2021-2022 Legislative Session.

FISCAL IMPACT

The bill would have an indeterminate negative fiscal impact on the DHHS and no impact on local units of government. The Department would incur the costs for staff or support provided to the Council. Members of the Council would serve without compensation; however, they could be reimbursed for actual and necessary expenses incurred while serving.

The typical annual costs to support an advisory council can range from \$10,000 to \$200,000 depending on the travel expenses and staff demands of the Council. The Fiscal Year 2023-2024 DHHS budget, Public Act 119 of 2023, included a total of \$200,000 GF/GP (\$70,000 GF/GP in ongoing funding and \$130,000 in one-time funding) and boilerplate to support the efforts of the Council.

Fiscal Analyst: Eilyn Ackerman

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This analysis was prepared by nonpartisan Senate staff for use by the Senate in its deliberations and does not constitute an official statement of legislative intent.